

Online supplementary file 1 - Interview guide

Theme 1 - The first phase

At first, I would like to hear you, if you want to tell a little about that period where you began to suspect that there was something wrong with your child's vision?

- What happened? How did you notice it?
- Who did you address with your concern?
- What was the timespan from your first concern until you talked to someone about it?
- Or was it someone else that noticed it? (health nurse, GP)
- How did they take you in?
- What was your thoughts?
- Who did you share your thoughts with?
- What made you wonder?
- How did you experience this period?

The need for help and support for parents and their everyday life

- What did you think about/what were your concerns, before you knew the explanation of your child visual challenges/disabilities?
- What need for help did you have at that time?
- Who could you share your concerns with?
- What could they help you with?
- What couldn't they help you with?
- If you look back at that time, how would a normal day look like?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

Theme 2: Meeting the hospital

Let's move on to the time for the investigation of the specific reasons to the visual challenges – what was that like?

- What was your experience of this period?
- Which professionals did you communicate with?
- What worked?
- What could have been better?
- What could you have wished for?
- How did you experience the cooperation between departments?
- Did you experience any waiting time for examinations or conversations with specialists?
- What was your role in this period?
- Did you have to wait for development of symptoms before it was possible to determine a diagnosis?
- Did your child's diagnosis make any difference?
- Did the professionals explain the meaning of the diagnosis?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child at this time? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

At this time where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, synskonsulent, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were there any help or support you could have wished for in this period – that you didn't receive?

What help or support did you find most valued in this period?

Theme 3: From hospital to municipality

Let us talk a little about the time from your child was registered in the Danish Registry for the Blind and Partially Sighted Children (diagnosis) till you had your first contact with the synskonsulent.

- When you think back, how did you experience this period?
- What do you think worked well/not well?
- When you think back at this period, what surprised you the most?
- If you had some questions, who could you ask?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

Need for help and support

- What were your concerns in this period?
- What need for help and support did you have?
- Who did you turn to for help and support?
- What could they help you with?
- What couldn't they help you with?

At this period where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were there any help or support you could have wished for in this period – that you didn't received?

What help or support did you find most valued in this period?

Theme 4: The everyday life and the future

Until now we have been talking a lot about the past experiences. Now we move on to talk about your everyday life and your thoughts about the future

- What do you think takes a lot effort or time in your everyday life?
- What need for support or help do you have now?

- Do you have someone you can turn to for help and support?
- What can they help you with?
- What are they not able to help you with?
- How would you describe your role as a parent in this process?
- What have worked well?
- What could have been better?
- Would you say that your role as a parent in this process have changed over time?

Opportunities to support the child

- Did you feel that you have the right opportunities to support your child in this period?
(why/why not?)
- What need for help and support do you have now? (knowledge, rights etc.)

When you think back at this period of your life as a hole, do you then think that your child's visual impairment has had consequences for you;

- Relationship
- Friendships
- Work situation
- Economy

What is other people's reaction when you tell them about your child's disabilities?

Do you feel that the help you receive are of the quality and standard that you expect? (yes – no, please elaborate/tell more)

Theme 5: Closure

Now we just have some final questions.

- From your point of view what would you have wished that could have been different?
- If you were to give an advice for any future families, what would that be?
- If you were to give an advice to the hospital, municipality etc. concerning help and support for families in similar situations, what would that be?
- From your actual position, what have then been the biggest surprise?
- Do you have any comments or questions to us?

Thank you for your help and time!